EHDI Ad Hoc Conference Call
May 5, 2005
2:00 p.m. Est.

Hello?

Dr. Patel: Yes, this is Dr. Patel.

Participant: Hi, this is Christy from Arizona. I just wanted to let you know I've joined the call.

Dr. Patel: All right.

Announcer: Mute on.

Participant: Hello?

Participant: Hi.

Participant: Are we supposed to hear any music?

Participant: I don't know, I'm just waiting for it to start, as well [beeping].

Participant: It's 1:00--I mean 2:00 right? Am I early?

Participant: I'm a fellow listener, as well. I have 5:02 but I haven't heard anything yet.

Krista: Hi, this is Krista Biernath from CDC. We are just going to be a few minutes, and then we'll be starting. So you all are on at the right time. Thanks for joining in.

Participant: Hello?

Marcus: Oh, hi. This is Marcus from CDC EHDI.

Dr. Patel: Yes, this is Dr. Patel, from Chicago.

Marcus: Hi, how are you?

Participant: Okay.

Marcus: We're just going to wait a few more minutes to give people some time to join the call and then we'll start.

Participant: I'm in Richmond.

Participant: Connie Basel, public health, Illinois.

Marcus: Good afternoon.

Participant: Chris Vandenhoner from cochlear.

Marcus: Did everybody get the link to download the slides?

Dr. Patel: I'm trying it's not opening.

Participant: I have it up successfully. This is Stacy Jordan from Vermont.

Participant: I got them in Richmond.

Marcus: I printed them about ten minutes ago.

Participant: Okay now it's working.

Marcus: Those of you who just joined we're making sure everybody has slides downloaded successfully before we start. If you have any questions please let me know regarding the slides. My name is Marcus. Please let me know.

[beeping]
[beeping]
[music playing in background]
[beep]
[beep]

Marcus: To those of you who have just joined were you able to successfully download the slides?

Participant: Yes I was, just the one set, right?

Marcus: Just the one set.

Participant: Yes, I got them.

Marcus: Great, we're just going to wait a couple more minutes, let some more people join.

Participant: All right.
[beep]
[beep]
[beep]

Marcus: To those of you, who have just joined the call, were you able to successfully download the slides?

Participant: I had no problem.

Marcus: Okay, great. As I said, I think we're just going to wait about another minute or two, and then we will be starting.

Participant: Thank you.

[more beeps]
[beep]

Marcus: Good afternoon, my name's Marcus Gaffney. I'd like to welcome you all to the CDC EHDI call. Today's subjected will be the risk of bacterial meningitis in children with cochlear implants. Before we begin I'd like to just go over a couple of notes. If you can remember, keep your phones on mute during the call. That will be very helpful. Background noises can be hard when you're not on mute such as typing on keyboards and background conversations and these obviously as you can imagine are very distracting to our speakers. As a second note if you'll be asking a question today if you could please identify yourself first. These help the presenters and also for the captioning for todays call. For the people using that service so they can know who is speaking? And also, if we can just ask one question at a time when we come to that portion of the call. As I said the topic of today's call is the risk of bacterial meningitis in children with cochlear implants. Our first speaker will be Dr. Krista Biernath a developmental pediatrician with the CDC EHDI team. And we'll also have John Eichwald, an audiologist and the team lead for the CDC EHDI program speaking on today's call. Once again, the slides were available online and they were sent in a reminder e-mail yesterday the web address to download those. Did anybody have a problem reaching those slides? Okay, I'm going to take that as a "no." And at this time, I'd like to get going. But one last reminder, please remember to keep your phones on mute. Krista, are you ready?

Krista: Yes, I am.

Marcus: Okay, well without further delay --

Announcer: Please have your password and conference name available. To cancel your request, press star 0.

Krista: I'm going to be talking about the risk of bacterial meningitis in children with cochlear implants. The preliminary results of the 2004 investigation. As many of you know, this is a follow-up to a 2002 investigation that was published in the New England Journal of Medicine in August of 2003 by Reefhuis, et al. I'm going to take you back to the 2002 study to discuss the background of this, and then work up to the most recent investigation. So the first slide, in June of 2002, the FDA reported 15 cases of meningitis in recipients of cochlear implants from one manufacturer. And this was in both adults and children. More reports were received later by other companies. So in early July of 2002, the FDA contacted CDC, the NCID which is the center on infectious diseases, regarding help. NCID then contacted the National Center on Birth Defects and Developmental Disabilities, where the EHDI team is located. So really, these two investigations have been a collaboration between these three entities. In July of 2002, the FDA put out the first public health notification on their website, and more reports were received. This was very quickly followed by a voluntary recall in the United States --

Announcer: Coordinator, do I have anyone online? Do you require assistance?

[beeping]

Krista: The next slide is just a background of cochlear implants. Cochlear implants are marketed in the United States by three companies. They were approved in the United States by the FDA for adults in 1985. In 1999, they were also approved for children over the 24 months of age. In 1999, they were approved for children over 18 months of age and then in 2000, for children over 12 months of age. The current figures as of April of this year are that in the United States, there are over 19,000 adults and 11,000 children that have received a cochlear implant. The next slide just shows a diagram of cochlear implants. This is a general cochlear implant model. They all are slightly different. They all have a transmitting coil and a receiver, and an electrode array which is inserted into a cochleostomy or an opening in the cochlea that's surgically created. Some of the models also had a positioner and this was a small silastic wedge inserted through the cochleostomy and into the cochlea and this positioner was used to press the electrode array up closer to the medial wall of the cochlear which facilitated transmission.

The next slide describes the study population. This consisted of a cohort of 4,000-plus children that we identified who had cochlear implants in the United States. This cohort was used for both the 2002 investigation and the 2004 investigation. These children received a cochlear implant between January 1st, 1997, and August 6, 2002. And at the time they received the implant, they were less than 6 years of age. These children were identified from warranty registrations that were routinely collected by the companies. –Approximately 95% of all warranties are estimated to be returned to the manufacturers. Therefore, th cohort is expected to be about 95% complete.. In total, 4,264 children were identified for the 2002 investigation.

Participant: Is that a manufacturer?

Krista: One extra child -- I'm sorry? Did you have a question? Is that a manufacturer?

Participant: Yes.

Krista: I'm sorry, could you clarify the question?

Participant: I'm not familiar with the term "cohort."

Krista: Thank you. I will clarify that. A cohort is simply a group of children, or a group of any subjects in a study, so any child with a cochlear implant who was implanted between those dates and who was less than 6 years of could have been added to our group if they were identified. And then that group is called a cohort. Does that answer your question?

Participant: Yes, thank you.

Krista: So the identified cases of meningitis for the 2002 investigation occurred between or were reported between 1997 and September 25, 2002. Cases that were reported later – or between

September 2002 and December 2004 were included in the 2004 investigation.. Next slide, the case definitions of bacterial meningitis for the 2002 and 2004 investigations, were identical. As you can see, we categorized cases into definite probable, and possible cases. And we used very specific definitions for each of those categories..

Next slide, the case ascertainment or how we identified the cases between 2002 and 2004. In the 2002 investigation, we contacted manufacturers. We sent out surveys to 4,000-plus families, and parents responded back to the surveys. Approximately 53% of the parents responded, so it was a very successful survey. And we did identify children with meningitis through the surveys. We also identified children with bacterial meningitis through the FDA's adverse reporting system. We also requested any reports of meningitis through the state health departments and the CDCs surveillance system. But no cases were identified through these means. For the 2004 investigation, all cases were identified through the FDA adverse event reporting system. Case reports were also requested through the CDC surveillance system, through state health departments, and contacts with the three manufacturers of FDA cochlear implants although we didn't dentify any cases through these means.

The next slide is the results of the 2002 investigation.. If you would like further information on these results, thishe article is available, for any of you who would like further information, in New England Journal of Medicine, July 31,, 2003. In the 2002 investigation, 29 episodes of bacterial meningitis were identified in 26 children, so 3 of the children each had two cases of bacterial meningitis. This is post-implantation bacterial meningitis. These episodes do not include bacterial meningitis in children who developed pre-implantation meningitis and subsequently lost hearing These children were only included if they developed bacterial meningitis after implantation of a cochlear implant. The time from implantation of the first episode to meningitis ranged from one day to 36 months post –implantation. . Two children had bacterial meningitis 24 months or later. The other 24 children developed meningitis less than 24 months post-implantation.. The median time was 2 months. The incidence of meningitis in the 2002 investigation caused by *Streptococus pneumonia* was 138 cases per 100,000 person-years. And this is more than 30 times the incidence of a cohort of the same age in the general U.S. population. Post-implantation of bacterial meningitis was strongly associated with the use of an implant with a positioner. The other significant association was radiographic evidence of a malformation of the inner ear in combination with a cerebrospinal fluid leak. We continued to watch our cohort, and we continued to follow FDA's adverse reporting system, and we found that after September 2002, bacterial meningitis continued to be reported post-implantation. Therefore, we undertook a follow-up 2004 investigation, looking specifically at the time period post-implantation as the 2002 investigation had reports of post-implantation meningitis only 24 months or less with the exception of 2 children. At the time of the 2004 investigation, a greater number of the children in the cohort had received their cochlear implant greater than 24 months post-implantation than at the time of the 2002 investigation.

The next slide shows that at the time of the 2004 investigation, 67% of the children without the positioner,were at least 48 months post-implantation. Whereas, 27% children with a positioner were at least 48 months post-implantation. Looking at it another way, approximately 70% of the children with an implant with a positioner were less than 48 months post-implantatio.. In the 2004 investigation, 12 new episodes of post-implantation bacterial meningitis were identified in 12

children. The time between implantation and occurrence of meningitis was greater than 24 months for six of the 12 episodes: all six children had cochlear implant models with a positioner.

The next slide shows the 2002 and 2004 investigations combined. What we found was there were 41 episodes of bacterial meningitis identified in 38 children. Your slides say 36. I apologize for that. It's 38. The time from implantation to diagnosis was greater than 24 months in 8 of the 41 episodes. Seven of these 8 children had a cochlear implant with a positioner. We then restricted the analysis to children who received an implant between 1999 and 2002, which was the time period that the positioner was on the market. To make these two groups as similar as possible, we did not include the children who received implants between 1997 and 1999 because a positioner wasn't available during that time.

On the next slide you'll see a table of the incidence rates of bacterial meningitis in children with cochlear implants with and without a positioner. This is a comparison of time to meningitis since cochlear implant surgery, 1999 to 2004. You can see on the left the time period these children developed meningitis post-implantation ranging from 0 months up to 37.9 months. You'll then see two main columns, positioner and no positioner. During the 37.9 months, the number of cases with a positioner was 28, and the number without was 8. This only adds up to 36 episodes; as mentioned previously, there were 41 episodes. This discrepancy is because this particular analysis was restricted to the time period Between 1999 and 2002. The highlighted rows show the time period from 24 months to 47.9 months. Please note that the episodes between that time period occurred in children with a positioner. So the incidence for the entire time, from 0 to 47.9 months, for children with a positioner was 915 episodes per 100,000 person-years. Whereas, for the children without a positioner during that time period in our cohort was 85 episodes per 100,000 person-years.

The next slide brings us to the conclusions resulting from the 2004 investigation. These data find that the risk of occurrence of bacterial meningitis extends beyond 24 months for children with cochlear implant models with a positioner. As far as without a positioner, we have not followed this cohort past 48 months, so we can only speak to the time period of 48 months, and less. Thus, it ill be important to continue to follow this cohort.

Next slide concerns recommendations. The updated findings support vigilance for signs and symptoms of infection by healthcare providers and by parents of all children with cochlear implants. This is both with and without a positioner. Vigilance is important beyond 2 years post-implantation, particularly in children with a positioner. However, vigilance should continue, also, for children without the positioner. All children with an implant, with and without a positioner and all potential recipients of implants should receive pneumococcal and *Haemophilus influenza* Type B vaccinations according to the current recommendation schedule for children with cochlear implants. We do have a couple of case reports of children who had cochlear implants without the positioner. The parents requested the vaccination, but were told that because the children did not have the implant model that was at risk, and therefore the vaccines were not necessary. I want to point out that it's very, very important that all children with cochlear implants receivethe vaccinations that are recommended. In addition, as John is going to elaborate on, continued surveillance is needed.. And this continued surveillance, in order to be comprehensive, state surveillance is going to be really key.

The next slide talks about further information. The citation for Reefhuis, et al, is listed. Also, the results of the 2004 will be published in *Pediatrics*. I don't have the date for that yet but we'll soon find out. As far as pneumococcal vaccinations for cochlear implant candidates and those who have received cochlear implants, the latest recommendations are in the MMWR, and the link to that is provided. The link for the most current immunization for all children and adolescents was issued in 2005 is also listed. Finally, the CDC's early hearing detection and intervention program has a section on cochlear implants, and this will be updated once the 2004 article has been published.

Marcus: Thank you ever so much, Krista. Are there any questions at this time for Krista?

Participant: I have a question.

Participant: I had a question.

Marcus: Okay, if the first person who spoke could go first.

Participant: My name is Walter Nance in Richmond. And perhaps I missed it, but it sounded like you did not contact parents to get data for your 2004 survey. Even though this was your best ascertainment source for the 2002 survey and I wondered if that is correct or not.

Krista: Yes, this is correct. I'm sorry; I'm watching the captioning so there's a small delay here. That is correct what you stated. For the 2004 investigation, we did not have all of the sources for data that the 2002 investigation had. We had hospitalization records for the meningitis episodes. Whereas the 2002 investigation, we had parents, primary care providers, hospitalization records, and also implantation records. As far as case ascertainment, we did not talk with the parents. However we do feel that the ascertainment is fairly reliable, because of knowledge of the information the 2002 investigation provided making the parents and providers aware, and would, we assume, be more willing to report.

Participant: A related question. In your control series where you determine the frequency of meningitis in infants who did not have cochlear implants, am I correct that you used a source, or your data, that did not identify any of your cochlear implant patients?

Krista:Correct. Actually, that was in the 2002 investigation. What we did was compare the incidence to children in the general U.S. population. We were not able to look at children who have a hearing loss without cochlear implants. Data for bacterial meningitis in all children with hearing loss is not available.. This is another topic that John is going to talk discuss.. If we can get these data, we can make that comparison. Did that answer your question?

Participant: But none of your patients with meningitis and a cochlear implant were reported to that source simply because they had meningitis. Is that correct?

Krista: They were reported because of meningitis. We found the cohort, and then looked for the children who were reported with meningitis. Does that answer?

Participant: Not really, but I guess it's not important.

Post conference note: Our source was the FDA's Adversen Event Reporting System. This system is designed to collect information on adverse events that may be associated with an FDA approved product. Therefore these reports of bacterial meningitis were episodes that were possibly associated with cochlear implants. Episodes of bacterial meningitis that are not potentially associated with an FDA approved product are not usually reported.

Krista: If you can send me an e-mail, I might be able to answer better.

Participant: Okay.

Marcus: Were there any other questions at this time?

Participant: Yes, this is Chris Vandenhoner from Cochlear Americas. Can you tell us anything about the vaccination history of the new cases identified between 2002 and 2004?

Krista: That's a very good question. Because the sources were different between the 2002 and 2004, we were able to collect vaccination information on children with bacterial meningitis through primary care providers and through other records that the 2004 investigation didn't have. So although we obtained some information on immunizations from meningitis hospital records, we don't feel that this is fully reliable.

Marcus: Are there any other questions?

Participant: Can I ask a follow-up question? Are there any among the new cases where you are confident that vaccination had been against the pathogen that was identified had been received?

Krista: We do have a couple of children who we feel fairly confident that they reported a vaccination history correctly. And this was because they made reference to the article, and told exactly how they got this information. As far as serotyping, the samples, unfortunately, were discarded and so we don't have the serotyping results of those. Does that answer your question?

Participant: Yes, thank you.

Marcus: Were there any other questions before we continue?

Participant: I have --

Participant: I had one more question regarding the immunization recommendations. The MMWR of 2003 recommended the pneumococcal vaccine for specific cochlear implant models. But in a previous slide, you indicated all children with implants should get that vaccine? Could you clarify that?

Krista: The MMWR article that I'm thinking of and I wish I could pull it up on my computer right now, talks about children, and all children with cochlear implants. I'm going to confirm that, since this question came up. Do you have my e-mail address?

Participant: Um, I'm not sure. I don't think so.

Post conference note: The clarification on this question is provided Dr. John Moran, Captain, United States Public Health Service, Acting Chief, Bacterial Vaccine-Preventable Diseases Branch, National Immunization program: Please see below.

"According to the MMWR of August 8, 2003 / 52(31);739-740 which can be found at http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5231a5.htm:

The 2003 MMWR recommendation is that children with ANY model of implants receive pneumococcal vaccine. And PCV7 is not indicated for anyone over 5 years of age. A 12 year old with an implant should receive a single dose of PPV23. The MMWR article states:

'Because the rate for pneumococcal meningitis is higher in children with cochlear implants and *Streptococcus pneumoniae* is the most common pathogen causing bacterial meningitis in cochlear implant recipients of all ages with meningitis of known etiology (*2*,*3*), ACIP recommends the following for persons who have or are scheduled to receive a cochlear implant (Table):

- Children aged <24 months with cochlear implants should receive PCV7, as is universally recommended; children with a lapse in vaccination should be vaccinated according to the catch-up schedule issued after the PCV7 shortage resolved (*4*,*5*).
- Children aged 24--59 months with cochlear implants who have not received PCV7 should be vaccinated according to the high-risk schedule; children with a lapse in vaccination should be vaccinated according to the catch-up schedule for persons at high risk issued after the PCV7 shortage resolved (*3*,*4*). Children who have completed the PCV7 series should receive PPV23 ≥2 months after vaccination with PCV7 (*3*).
- Persons aged 5--64 years with cochlear implants should receive PPV23 according to the schedule used for persons with chronic illnesses; a single dose is indicated (*6*).
- Persons planning to receive a cochlear implant should be up-to-date on age-appropriate pneumococcal vaccination ≥2 weeks before surgery, if possible.' "

TABLE. Recommended pneumoccocal vaccination schedule for persons with cochlear implants, Advisory Committee on Immunization Practices, 2003

Age at first PCV7 dose (mos)*	PCV7 primary series	PCV7 additional dose	PPV23 dose
2–6	3 doses, 2 months apart†	1 dose at 12–15 months of age§	Indicated at ≥24 months of age¶
7–11	2 doses, 2 months apart†	1 dose at 12–15 months of age§	Indicated at ≥24 months of age¶
12–23	2 doses, 2 months apart**	Not indicated	Indicated at ≥24 months of age¶
24–59	2 doses, 2 months apart**	Not indicated	Indicated¶
≥60	Not indicated††	Not indicated††	Indicated

* A schedule with a reduced number of total 7-valent pneumococcal conjugate vaccine (PCV7) doses is indicated if children start late or are incompletely vaccinated. Children with a lapse in vaccination should be vaccinated according to the catch-up schedule (CDC. Pneumococcal conjugate vaccine shortage resolved. MMWR 2003;52:446–7).
† For children vaccinated at age <1 year, minimum interval between doses is 4 weeks.
§ The additional dose should be administered ≥8 weeks after the primary series has been completed.
¶ Children aged <5 years should complete the PCV7 series first; 23-valent pneumococcal polysaccharide vaccine (PPV23) should be administered to children aged ≥24 months ≥8 weeks after the last dose of PCV7 (CDC. Preventing pneumococcal disease among infants and young children: recommendations of the Advisory Committee on Immunization Practices. MMWR 2000;49(No. RR-9).
** Minimum interval between doses is 8 weeks.
†† PCV7 is not recommended generally for children aged ≥5 years.

Krista: Okay. For anybody who wants to ask questions via e-mail, my e-mail address is kbiernath@cdc.gov. Send me any of the questions, and I can confirm those for you.

Participant: Thank you.

Participant: Can I ask one question?

Marcus: Sure.

Participant: From Richmond, what is the relative risk for patients without a positioner, then, of developing meningitis?

Krista: The incidence for children without a positioner between 0 months and 63 months post-implantation was 915 cases per 100,000. Does that answer your question?

Participant: And how is that compared to normal? For the controls?

Krista: This was not a case-control study. This was a cohort study for the 2004. However the 2002 investigation included a case control study. . So we did not compare all of the children with a case so that is one limitation of this.

Participant: Okay, if we have more we'll ask by e-mail. Thanks.

Marcus: Okay. I think at this time, if we can get going to our second speaker, John, and then any other questions we have, we can just ask towards the end of the call, if that's okay with everybody. Our next speaker is John Eichwald. Are you ready, John?

John: Yes, I am.

Marcus: Thank you, and thank you, Krista.

John: Thank you, Krista. Buenos-días, buenos-tardes and happy Cinco de Mayo. As Krista pointed out there really is a need for continued surveillance. We feel that this is an issue we need to address at multiple levels. This is a public health concern. Since the development of the cohort was used, many children have received the cochlear implants, although none have received the model with the positioner, as that was voluntarily removed from the market. But we feel it's very important to continue to follow children with cochlear implants for bacterial meningitis through ongoing surveillance. What are we doing at the CDC?

Well, we continue to work with the FDA, and we're continuing to also work with CDC's active bacterial core surveillance or ABCS program. There are some limitations though with this kind of surveillance; limitations [have] been the ABCS program covers only 10 sites in the United States. This is not a nationwide program. Where we're getting most of our information at this point in time comes from the FDA adverse event reporting system. And they basically maintain the only

registry of cochlear implant events in the U.S. and it monitors implant safety, but it is really not designed for surveillance research and prevention measures. And without accurate data this public health concern cannot be adequately addressed. Presently what's going on at the state level, the national notifiable disease surveillance systems does have meningitis reported. This disease reporting is mandated only at the state level, and the diseases that are reported by each state varies. For states that are mandated to report streptococcus pneumonia, NEDSS [National Electronic Disease Surveillance System] recommends reporting invasive disease in children less than 5 years of age and so this in the long term will probably not help us in terms of long-term surveillance. Most states do not collect data on cochlear implant status, and the reporting of NEDSS to the CDC by the states is voluntary. What's going on also at the state EHDI programs?

At the present time, we do collect information nationally through the DSHPSHWA [Directors of Speech and Hearing Programs in State Health and Welfare Agencies] surveys. And the DSHPSHWA shares this information with CDC and that includes information on screening, diagnosis and intervention. We feel some EHDI systems are set up to gather information about the use of cochlear implants. However, this data is not being reported to the CDC. At the present time, we don't know if any state EHDI systems are currently collecting information about the occurrence of bacterial meningitis. We feel that few EHDI programs have on going relationships with the state infectious disease surveillance systems. What are our next steps?

We will continue to work with ABCS program and the FDA. We continue to be in contact with the state epidemiologists and we will be requesting that all states modify their infectious disease reporting system to include at least two questions. And those are:

> Is the person deaf/hard-of-hearing?
> And the second question: Does the person have a cochlear implant?

We want to continue to work with state and territorial EHDI programs to encourage and facilitate states and territories reporting cases to CDC EHDI. What can state EHDI systems do? Well, become familiar with your state or territory disease reporting laws. Support collaboration between your infectious disease program and your program. We'd also encourage people, programs, to work with audiologists, medical home for alternate opportunities for reporting streptococcus pneumonia and in particular for children with cochlear implants 5 years or older in the states that mandate reporting for only those younger children, and for all children with cochlear implants in states that do not mandate this reporting.

Marcus: excuse me John. If I can remind to get people to put their phones on mute. We're picking up background conversations which are very distracting. Thank you.

John: Thanks, Marcus. At this point in time what I'd like to do is take questions if you have them, and then I've got some questions basically for the audience, too.

[beeping]

John: So questions at this point in time?

Participant: Yes, I have one.

John: Go ahead.

Participant:: This is Stacy from Vermont. Do you know how many states are mandated to report at this point?

John: To report what?

Stacy: To report cases of just meningitis?

John: I don't have that information at my fingertips. I think probably the best thing to do is go out to the Council of State and Territorial Epidemiologists, CSTE and you might be able to check on that there. Other questions?

Participant: This is Connie from Illinois. Could you say that website one more time, please?

John: Yeah. It's actually on the last of the slides. It's the council for state and territorial epidemiologists, and that's www.cste.org. And also find your state epidemiologist, there's a listing of each state epidemiologist on that website. If there are no questions for me I'm going to start questioning you.

Participant: My first question is -- is there any state EHDI system currently collecting information about the occurrence of bacterial meningitis? I guess I'll take that as a "no."

Participant: Well, this is Ellen from Rhode Island. We -- I mean, I have asked our state epidemiologist; they are certainly happy to report [that] we haven't had any cases that I'm aware of. It's not like we have to collect -- such small numbers, we would be looking for it and collecting in partnership. But we're trying to keep our eyes out for it. And it hasn't happened yet, to my knowledge.

John: You actually have that in your database?

Participant: No, it's not in a database because we're not going to create a field for what we feel will be a very, very rare event.

John: Okay. This sort of follows up as part of that question and that is: Are there EHDI programs that have an active relationship with their state infectious disease surveillance systems?

Participant: This is Deb Lochner Doyle from Washington State and yes, we do. We also have it within our EHDI system a field specific to whether or not a child has received a cochlear implant, and then we have a notes page. So as that child receives further follow-up the audiologist can go in so our expectation would be that if that child did develop meningitis, that would be entered by the audiologist in the "notes" page.

John: Great, thanks. And I've got sort of follow-up for that. And that is if yes, do you have a recommendation to other programs, how you would establish this relationship?

Deb: Hmmm, that's a tough one. I think that how I got more involved -- I mean, I'm -- we have overall managers team meeting where all of the managers get together on a periodic basis anyway so that's how I've gotten to know the people in epidemiology, et cetera. But when the 2002 study was going on and the state epidemiologists were contacted and our state epidemiologist is in our infectious disease program then they contacted me as the EHDI person and basically said let's work on this together. So we formed our relationship kind of at your insistence.

Participant: This is Ellen in Rhode Island and I would echo that. When these discussions first started coming out of CDC and the need for increased state surveillance, I happened to know the people anyway, but I made it a specific point of saying we're trying to do this and they said sure, we'd be happy to help just give us direction and it's taken off from there.

John: Thanks, Ellen and Debra. For those that didn't answer, are there barriers to contacting your state epidemiologist and requesting that would infectious disease report forms to be modified? What about barriers of reporting cases to CDC EHDI? If there are no barriers, we should all be doing it, right? Okay. Does anyone have an innovative idea as to how EHDI programs can work with audiologists and the medical home for alternative opportunities for reporting? And in particular, we're looking for children with cochlear implants who are age 5 and older.

[beeping]

John: And those in states where cochlear implants for children with cochlear implants in states that do not mandate the reporting. This is a bright group. You should be able to come up with something.

Participant: John, this is Deb again in Washington. I guess my dilemma here is that it is a notifiable condition in my state. I would expect that the epidemiologists are already asking about cochlear implants, and they would notify us. So I kind of think that the real issue is whether or not we have those data, and then are sharing them with CDC.

John: Right.

Participant: This is Ellen. We, like, we're very similar to Washington state. But for those people who are collecting data in their EHDI system around cochlear implants, to the extent that we know a child has had a cochlear implant, and to the extent that you know who the primary care physician is, you can send just from your system, develop a reminder letter to -- that goes out once a year or however often, saying, just to remind you, this is an issue that we're concerned about. Please let us know if anything has happened in this past year. Just something to jog their memories.

John: Good. Thanks, Ellen. Is anybody else doing anything similar to that with notifications.

Ellen: We're not doing it but you asked for ideas.
[laughter]

John: Oh, I thought you were already doing it.

Ellen: No. But it would be an idea of how to reach out because people don't remember to report those.

John: Right.

Ellen: Especially since it's not mandated. Even when it is mandated, they forget.

John: Okay. Well, one thing again I just encourage state EHDI programs to become familiar with your disease-reporting laws, and try to establish some collaboration with your infectious disease program. I think that this collaboration could really help us in this endeavor.

Participant: Any of the EHDI programs contact the parents of deaf children annually? I wonder if that would be a mechanism for identifying cases.

John: That's a good question. Answers from the crowd?

Participant: This is Connie from Illinois. We have the children identified especially as our database gets better and better data reported from the hospitals and then the follow-up but we aren't contacting those families at this time.

Krista: John, this is Krista. I just wanted to mention that one of the things that people really want to know is how post-implant meningitis in this group of children compares to meningitis in children who have a hearing loss. So it would be really helpful if states could follow up with not only children with cochlear implants, but all children, and to report all.

John: Thank you, Krista. I put a note down here to mention that. And I forgot, and I'm glad you did.

Participant: I have a question.

John: go ahead.

Participant: Do you have any recommendations from a national level? I live in a small state, but we have lots of bordering support where our families might -- we might have an i.d.'d child in our state but they go to a bordering state for cochlear implants or for their healthcare. And do you have any recommendations or future insights from a national level of how we would be able to share this type of information from state to state?

John: It's interesting you ask that. We are very interested in border-baby issues. From all levels, and that is, from screening of hearing loss and from enrollment in early intervention. We have begun some preliminary contact with some states to see what they're doing. A New England group has been discussing this. Marcus, do you want to just give us a 30-second update in terms of the project?

Marcus: Yes, of course, thank you, John. Basically, we began last November working with the group in the New England states, about 7 in total, just to look at different ways we could sort of respond to the border-baby issue. What we've been doing is having a regular series of teleconferences approximately every month. Part of this process has been looking at the different rules and laws in each state, and trying to determine what exactly is required to be able to report data to neighboring states about border babies. And we're looking at some different things, whether some sort of standardized agreement would be good to put in place or just verifying what can be done under current laws. As I said, this initiative has been going on - on an informal basis for a few months now. If you'd like any more information about it, I'd probably encourage you to please send me an e-mail, although we also had a teleconference last week on the whole subject of border babies, and that will be on the CDC EHDI website within about two to three weeks. And that might have some helpful information, too. Does that help?

Participant: Yes. Actually, Marcus, this is Stacy Jordan. I'm the new EHDI contact for Vermont so I look forward to hopefully helping see this process progress as time goes on.

Marcus: Great. We definitely look forward to working with you on it.

John: Thanks, Marcus.

Marcus: Thanks, John. Are there any other questions for either of our speakers at this time? John and Krista, are there any other points you'd like to bring up?

John: No. Enjoy the rest of your day.

Marcus: Okay. Just one last quick note: a transcript of this call will be available on the EHDI website within about 3 to 4 weeks. And that website is just simply www.cdc.gov/ncbddd/EHDI. If you have any questions, please let me know. And thank you for joining us today and thank you to both of our speakers. It's much appreciated.

[2:50 EST – end of call]